

Congenital Anomalies of the Limbs: Part II. Psychological and Educational Aspects

G. GINGRAS, M.D.,* M. MONGEAU, M.D.,† P. MOREAULT, M.D.,‡
M. DUPUIS, M.D.,§ B. HEBERT, L.Ps.,¶ and
C. CORRIVEAU, C.P.O.,|| *Montreal*

ABSTRACT

As a preparatory step towards the development of a complete habilitation program for children with congenital limb anomalies associated with maternal ingestion of thalidomide, the medical records of all patients with congenital limb anomalies referred to the Rehabilitation Institute of Montreal in the past decade were studied, and an examination and a thorough reassessment were made of 41 patients (21 males and 20 females). The medical and prosthetic aspects were dealt with in Part I of this paper. Part II describes, in a joint report, the results of psychiatric, psychological and educational assessments.

There was no evidence of major emotional disorder in any of the patients, although conflicts were intensified by the presence of the physical anomaly. No relation was found between intelligence, emotional adjustment and disability. The patient's attitude towards his disability and prosthesis is definitely influenced by the degree of parental acceptance of the handicap and by the character of the emotional undertones in the total environment. In order to favour the occurrence of the healthiest modes of development in these children, the authors believe that the medical profession should be made fully aware of the physical and emotional problems which may arise after the birth of a deformed child. It is considered very important that the mother should receive psychotherapeutic support as soon as possible after the child is born.

SOMMAIRE

Comme mesure préliminaire en vue de la création d'un plan complet d'habilitation destiné aux enfants frappés d'anomalies congénitales des membres par suite de l'ingestion de thalidomide par la mère, l'Institut de Réhabilitation de Montréal a passé en revue les dossiers médicaux de tous les cas qui se sont présentés à l'Institut au cours de la dernière décennie. On a également procédé à un nouvel examen et à un bilan complet de 41 enfants (21 du sexe masculin et 20 du sexe féminin). Cette première partie couvrait les aspects médicaux et prothésiques du problème. La deuxième partie, dans un rapport commun, passe en revue les résultats du bilan sur les plans psychiatrique, psychologique et éducatif.

Chez aucun des malades, on n'a trouvé de trouble émotif majeur, bien que les conflits aient été aggravés par le fait de l'infirmité. On n'a pas constaté davantage de relation entre l'intelligence, l'adaptation émotive et l'infirmité. Par contre, l'attitude du malade vis-à-vis son handicap est nettement influencée par le degré d'acceptation par les parents et le caractère des répercussions du milieu total. Pour que ces enfants puissent bénéficier d'un développement aussi normal que possible, les auteurs estiment que le corps médical devrait être parfaitement conscient des problèmes physiques et émotionnels qui peuvent survenir après la naissance d'un enfant difforme. On considère comme très important que la mère reçoive le support, d'une psychothérapie aussitôt que possible après la naissance de l'enfant.

AS A preparatory step towards the development of a complete habilitation program for children with congenital limb anomalies associated with maternal ingestion of thalidomide, the medical records of all patients with congenital limb

anomalies referred to the Rehabilitation Institute of Montreal in the past 10 years were studied, and an examination and a thorough reassessment were made of 41 patients (21 males and 20 females). The medical and prosthetic aspects were dealt with in Part I of this communication.

In this Part the psychological and educational aspects of the total research project will be examined. The selection of subjects on whom the findings are based does not conform to strict laws of sampling. In fact, the group is sufficiently heterogeneous that we feel warranted in drawing con-

Part I, "Medical Aspects", was published in the issue of July 11 (91: 67, 1964).

*Executive Director, Rehabilitation Institute of Montreal, 6300 Darlington Ave., Montreal 26, Que.

†Chief of Service, Physical Medicine and Rehabilitation, Rehabilitation Institute of Montreal.

‡Formerly, Consultant in Psychiatry, Rehabilitation Institute of Montreal.

§Resident in Physical Medicine and Rehabilitation, Rehabilitation Institute of Montreal.

¶Head, Psychology and Vocational Guidance Section, Rehabilitation Institute of Montreal.

||Consultant in Prosthetics, Research and Training Unit, Rehabilitation Institute of Montreal.

clusions that are scientifically valid only for the population as a whole, without reference to specific age groups or types of handicap. As to ages, the group comprised six children aged 14 months to 5 years, 11 subjects aged 6 to 11 years, 10 adolescents of 12 to 18 years of age, and finally 14 adults of 19 years and over. They had more or less severe handicaps: one 14-month-old boy lacked both arms and one leg; one girl had no arms, and another, no legs. The remaining 38 subjects were born with different anomalies, in approximately equal number, of an extremity, hands, feet or fingers.

Had the age spread of these subjects been less extensive and had the types of anomaly been less varied more significant results might have been obtainable for a specific age group and anomaly. We must therefore emphasize that our conclusions apply only to this population and should not be regarded as applicable as a generalization to all persons born with congenital malformations.

Each of the 41 patients with a congenital limb defect was interviewed by both a psychiatrist and a psychologist; the latter also assessed intelligence and personality by standard intelligence scales¹⁻⁴ and a projective technique, namely, drawings of a "person" and of the "self".⁵ Approximately 50% of the parents were questioned about the child's development, schooling and social history, and details were obtained on the parents' reactions following the child's birth and their personal adjustment to his disability.

The results of psychiatric and psychological investigations are presented in a joint report in order that the common findings from separate observations and examinations may be stressed.

FINDINGS AND INTERPRETATION

Intelligence and Education

Of these 41 patients only four adults, between 25 and 36 years of age, and one 5-year-old child functioned at a low-average level of intelligence. The remaining 36 were endowed with intelligence quotients ranging from 92 to 135 (i.e. average to superior), the mean I.Q. being 104.5.

If there is any psychological maladjustment characteristic of persons with amelia or dysmelia, the intellectual level of functioning should not be considered to be a causal or precipitating factor. Further, it was found that the healthiest modes of adaptation were favoured by intellectual assets which fostered more adequate and stronger defence mechanisms and greater possibilities for compensation and sublimation.

It was difficult to ascertain the existence of any schooling problem in our subjects inasmuch as adjustment to school and classmates is too intimately linked with emotional maturity and the severity and acceptance of the handicap. It may be said, however, that well-adjusted subjects, no matter how severe the physical limitations, integrated into the school population with minimal

difficulty. Children living in a rural community must attend the school in their village. They face their non-handicapped classmates with greater success if they are already known to them, and if they have already established pre-school friendly relations. Difficulties, as will be explained later, appear with relatively greater intensity in children who have to integrate into new social and school groups. This happens, of course, more frequently to semi-urban and urban persons. Only one child, with a lower-extremity amelia, attends one of the two Montreal schools for crippled children; the other school-aged subjects are neither so handicapped nor so limited in their activities that they cannot be educated in regular schools.

Motor and Emotional Development

Contrary to expectations, congenitally malformed children of normal and superior intelligence develop an early and gratifying curiosity about their environment; they manage to explore outside reality almost as adequately as non-handicapped children. They use whatever functions their deficient limbs will allow or adequately compensate with their non-disabled limbs. Success or failure in their attempts to understand their world and to develop and master motor activities is determined not so much by their physical limitations as by the more or less anxious attitude of the mother. She may be overprotective and inhibit all forms of development, or she may force her child to achieve a mastery beyond his neuromuscular maturity. In most cases, the overprotective attitudes prevail.

We found no major emotional disorders (psychoses* or psychoneuroses†) in any of the subjects, even the most severely disabled, except in one adolescent who had delinquent tendencies; family background and social environment are thought to be responsible for this disorder, and the handicap was used as a rationalization to justify his anti-social acting-out. Nevertheless, many of them suffered from neurotic conflicts** or character defects‡ which are of the same nature as those

**Psychoses* refer to severe mental illnesses. This term is most often accompanied with an adjective that expresses the nature, etiology or dominant factor, e.g. organic, senile, hallucinatory, manic-depressive, paranoid schizophrenic. The psychotic differs from the neurotic in that the former lacks awareness of his morbid state and is suffering from a break with reality.

†*Psychoneuroses* are nervous diseases which have no known anatomical origin and which, although intimately associated with the person's psychic life, do not alter basic personality. These illnesses are always accompanied by a painful and excessive awareness of the morbid state.

(Both definitions translated and adapted from Porot.⁶)

***Neurotic conflicts* are emotional maladjustments which are well-nigh universal. Conflicts, although of a neurotic (or nervous) nature, are not as severe or as organized as a true neurosis, but rather an exaggeration of various patterns of reactions and of symptoms found in most people (Adapted from Alexander *et al.*⁷)

‡*Character defect* is not easy to define briefly and clearly. Many authors interchange the term with behaviour disturbance, neurotic character, character disorder, etc. The outstanding feature of this condition, which may vary in intensity, degree or severity, is that ego-alien impulses find outlet in actual behaviour or acting-out (truancy, destructiveness, lying, disobedience, etc.) rather than in neurotic symptoms (anxiety, phobia, enuresis, compulsion, conversion, etc.). Because the ego-alien impulses are often of an aggressively anti-social nature, patients often come in conflict with authority figures. (Adapted from Alexander and Shapiro.⁸)

found in non-handicapped persons. As in all other persons, these conflicts are conditioned by parental attitudes during the early years of life and specifically by the mother-child relationship, which directly influences the character structure of the child. Her child's congenital deformities or absent limbs intensify the mother's emotional reactions toward him, but the intensity and quality of these reactions are in keeping with her own character structure.

Mothers with obsessional or compulsive* personalities† early utilize the mechanism of denial toward their child's limitations and tend to force over-compensation. These mothers, owing to their own identifications, can accept somewhat more easily the handicap of their child; feelings of castration, objectified by the total or partial absence of one or more extremities, are not so strongly felt by this type of woman. Children of such obsessional mothers seem also to accept their handicap with less reaction and with greater ease; they are able to face their limitations with less anxiety and will integrate into the body image the presence of any prosthesis they may have to wear. Of course, this healthy adjustment should not be overemphasized, since conflicts do remain. Chances for a satisfying life, however, are greatly enhanced provided that their needs to overcompensate are gratified.¹⁰ Children of mothers with hysterical personalities** and strong oral components tend to react with greater emotional intensity and anxiety to the handicap, and their general adaptation is quite threatened; these deformed children will not readily accept a prosthesis at any age.

Throughout the first five years of life, children with limb deficiencies live in a close family circle where intimate social contacts are limited to parents, siblings and close relatives; the emotional reactions of these individuals are more important than those of strangers. The remarks and even morbid curiosity of strangers do not carry the same impact at this stage of their lives as they will later in life when they are in the process of breaking away from the protective familial attitudes. Children readily accept this overprotection against undue influence from a wider world and rely mostly on the mother to ward off environmental threats. It is a known fact that pre-school children are able to act out conflicts which have not yet been internalized or entirely expressed in symptoms. However, drawings reveal that these children cannot help but feel, consciously or unconsciously, the covert devaluating attitudes that underlie the

mother's overprotection or eagerness to have the child overcompensate.

Emotional problems appear better defined and more intense when the child enters the latency period. This stage of development coincides with the beginning of formal education and of a complex and diversified socializing process. Therefore, unless the child attends a special school for crippled children, where he can easily identify with others physically disabled, he is forced to shoulder the responsibility for his own adjustment to the new school world, to establish new types of relationships with adults, to ward off possible attacks from classmates and to make himself acceptable with, and sometimes despite, the handicap. It is not surprising to find that the complexity of this school environment may be somewhat traumatic; it strengthens the defence mechanisms and provokes an exaggeration of less normal modes of adjustment. The ability of the child to identify with these new key-figures is influenced by earlier parent-child relationships, and rigid and crystallized reactions may develop which greatly impede the chances of ever achieving a flexible and mature personality.

BODY IMAGE

It must be emphasized that children with congenital limb anomalies do not suffer a traumatic alteration of their body, as is the case of one who has an acquired disability.¹¹ This explains the absence of marked distortions in body image and the relative lack of anxiety due to a need to restructure self-perceptions.

These patients go through the same normal structuring process in regard to body image as do normal children. The "person" and "self" drawing tests, as well as interviews, suggest an early awareness of the partially or totally absent limb; the young child is definitely preoccupied with his disability. Most children, as young as three years of age, ask questions about the difference in their own two extremities or between their extremities and those of their normal siblings. This preoccupation does not seem, however, to indicate anything more than intellectual curiosity, similar to the questioning of any young child about the nature of things, their functions, etc.

The child's concern increases with the beginning of the latency period and reaches a peak at the onset of adolescence. Drawings clearly indicated that amelic patients between six and 13 years invest, consciously or unconsciously, the deficient limb with all their anxiety, regardless of their level of maturity. The handicap is always a source, more or less latent, of self-devaluation.¹² Even if tendencies to overcompensate are developed and gratified, the disability is already a sign of inferiority. Children with obsessional character structures reproduce, in the drawing of a "person", four complete extremities, but the handicapped body segment is drawn in much smaller dimen-

*Persons with an obsessional or compulsive personality tend to be punctilious, rigid, fastidious, formal and meticulous. They are overinhibited, perfectionistic, self-doubting, stubborn and parsimonious. Regression, reaction-formation and rationalization are their main ego-mechanisms of defence.

†Personality is defined by Noyes⁹ as "that functioning organization of the whole of an individual which evolves through a developing process". This organization may be structured along different lines; some types of personality have been identified and described, among which are the hysterical and the obsessional or compulsive personalities.

**A hysterical personality is characterized primarily by marked suggestibility, immaturity, proneness to self-display and a tendency to control the environment. Regression is the main mechanism of defence used by hysterical persons.

sions. The rest of the drawing is well structured and adequately proportioned; feelings of being diminished, although present, are limited to the handicap. They are able, however, to draw themselves either with the limb deficiency or with a prosthesis, revealing acceptance of the handicap and a capacity to adjust to their limitations. Hysterical personalities, who adjust less readily to their handicap, tend to draw both "person" and "self" with distortions of the impaired extremity and of most of the body, but are unable to depict the prosthesis in the drawing of "self"; they reveal strong feelings of self-depreciation which spread not only to the entire body image but also to the whole personality.

The intensity of phantasy life of adolescents and their sensitivity to the attitudes and reactions of their social environment are well recognized. It may be noted that the sense of value that is attached to the whole person appears to be intimately linked with the integrity and appearance of the body.¹³ We found that the subjects' social interactions, real and imagined, which so much as touch upon their disability, evoke a definite and constant signal of threat;¹¹ these subjects therefore tend to limit their social contacts and try as best they can to camouflage the involved body segment. Their reaction is more in evidence when the malformation involves the upper extremities. When meeting new groups of people in social life or at work, they relive the same emotions. All obsessional subjects manage, during later adolescence, to be much less sensitive to the reactions of strangers and even manage to achieve some measure of social and occupational success. Hysterical subjects are never able to attenuate their sensitivity; feelings of rejection and of personal failure are always associated with their intensely felt limitations.

It is a known fact that the earlier a child is trained to wear a prosthesis, the easier it will become a part of his body image. This, of course, does not reduce the significance of the previously mentioned fact that personality structure remains an important factor in the acceptance or rejection of a prosthesis. These children accept most readily an artificial leg or foot. If, however, they have found ways of using a partially absent upper extremity and of overcoming some of the difficulties imposed by limited motor functioning, acceptance of a prosthesis is more difficult, even if it is provided as early as six or seven years of age. Some of the children prefer the awkward but relatively adequate upper extremity stump to the frustrating process of prosthetic adaptation. The artificial arm or hand is, therefore, often perceived as a device which forces a child to give up already acquired motor habits and to integrate into the body image a foreign object that is at first of rather limited value. Parents readily accept the artificial legs; some of them, however, show a negative attitude

towards an upper extremity prosthesis, even cosmetic hands.

The possible existence of phantom limbs was investigated with great care. Contrary to the opinion of Weinstein and Sersen,¹⁴ such findings were not reported by any of the sample members. However, a 9-year-old girl, with amelia of both upper extremities, described what could be interpreted as a phantom right arm. It was not possible to verify the objectivity of this phenomenon, although the opinion was advanced that it was rather the product of a very active phantasy life and of wishful thinking.

PROPHYLACTIC MEASURES

The occurrence of congenital absence or malformation of a limb is felt more intensely by the parents than by the affected children. The latter at first perceive their disability and limitations through the parental attitudes of acceptance or rejection and through their objective or disturbed outlook. A realistic understanding of the handicap by the parents can only favour a better emotional adjustment by the children and foster an adequate and constructive use of rehabilitation services, as well as social and educational facilities.

Even 10 years ago it was not unusual for the doctors and the entire medical team to suggest to mothers that they leave the deficient offspring at the hospital until the whole family had regained their emotional equilibrium, temporarily shattered and severely threatened by the birth of such a child; some parents reported a lack of awareness of rehabilitation possibilities or they were told to postpone consultations with specialists until the child had reached early adolescence.

The medical profession and members of the health team should be fully aware of the kinds of physical and emotional problems occasioned by the birth of a child with malformations. This should include an awareness of the intense emotional reactions that occur in a mother who gives birth to such a deformed child, which should occasion the adoption of all possible measures of reassurance concerning the prognosis for a relatively normal physical adjustment.

Management of emotional reactions of a mother faced with a congenitally handicapped child is so important that they require more intensive and deeper psychological aid than is within the competency of the general medical doctor or of his staff. We feel that each mother needs supportive psychotherapy that will, among other things, not only lead to a better understanding of her diverse and complex emotions, but, most important, will also favour an abreaction of her fears, apprehensions and feelings of guilt and will diminish projective elements inherent in such a traumatic event. Psychotherapeutic interviews should foster a realistic perception of the handicapped child that considers not only his limitations but also his assets. Mothers

who have not had a chance to abreact in respect of their guilt feelings and apprehension, suppress in their own children free expression of similar affects; hostile and depressed reactions on the part of the child only stir up emotions which the mother cannot face within herself.

Prostheses should be fitted as soon as a child has achieved an adequate level of motor differentiation. Early fitting enables the child to include the presence of this artificial segment into his body image, and favours better and more gratifying explorations of the environment; it also permits the child to engage in a diversity of activities which can only be enriching to his personality.

CONCLUSIONS

The occurrence of a congenital limb anomaly in an infant is more intensely felt by the parents than by the affected child. Such a deformed child who is reared in a relatively normal family and social and educational environment is not condemned to the life of an outcast. In fact, these children face less serious problems than is generally thought by uninformed persons, provided that the emotional reactions aroused by the birth of a congenitally disabled child are not given undue emphasis on the part of those concerned.

In this series the intellectual abilities of affected persons ranged from low average to superior levels, the mean I.Q. being 104.5. None experienced educational difficulties different from those encountered by most handicapped children. Any school or learning problems that were mentioned by the parents were directly related to the child's general emotional adjustment or to the availability of public or specialized schools adapted to the physical condition.

Greater intellectual capacities favour rather the development of strong ego defence mechanisms, providing greater possibilities for compensation and sublimation.

Children with amelia and dysmelia are able to explore their surroundings, despite their limitations, with more ease and satisfaction than expected. Parents reported that these children developed an early curiosity; owing to their normal intellectual capacity, the subjects are able to gratify their normal desire to experiment with the environment, using whatever function remains in their deficient limb or compensating by the use of the non-handicapped extremities.

There was no evidence of major emotional disorders in our population, except in the case of one patient who exhibited anti-social tendencies. However, conflicts, whether severe or mild, were always intensified by the presence of the physical anomaly. It was found that the mother-child relationship directly influenced character formation in the child.

The child's body image develops as normally as in non-handicapped children; the authors found no severe or marked distortion of the body schema

during the first years of life. Anxiety became more intense with the onset of the latency period and reached a peak in early adolescence. Anxiety and related emotional conflicts were almost always invested in the abnormal extremity.

The children whose parents are least affected by the presence of a congenital limb defect will adjust to the use of a prosthesis with much less resistance, while the children whose mothers have a hysterical personality with strong oral components hardly ever accept their handicap. These latter find it much more difficult to adjust to the presence of any kind of prosthesis, even when it is provided at an early age.

The medical profession should be fully aware of physical and emotional problems that may arise following the birth of a deformed child. It is most important to provide the mother with the support of psychotherapy as soon as possible after the child is born. This therapy should be the responsibility of psychiatric and psychological specialists.

GENERAL CONCLUSIONS (PARTS I AND II)

From the medical and psychological points of view, patients with congenital deformities should be seen and evaluated by a habilitation team, and habilitation measures should be started at the earliest possible date after birth. Prosthetic training, where applicable, should be initiated early. Psychotherapeutic support should be given to the parents, particularly the mother, as soon as possible after the birth of a child with congenital deformities. The medical profession should be made aware of the vastness of this relatively unexplored field.

The assistance and advice of Dr. K. C. Charron, Director of Health Services, Department of National Health and Welfare, Ottawa; Dr. A.-R. Foley, Chief, Epidemiology Division, Department of Health, Quebec, Quebec City, P.Q.; and Dr. Bertrand Primeau, Medical Director, Rehabilitation Institute of Montreal, are gratefully acknowledged.

REFERENCES

1. BARBEAU, G. J. ET PINARD, A.: *Epreuve individuelle d'intelligence générale de l'Institut de Psychologie de l'Université de Montréal, Le Centre de Psychologie et de Pédagogie*, Montreal, 1951.
2. DOLL, E. A.: *Vineland social maturity scale*, Educational Publishers, Minnesota, 1957.
3. Terman, L. M. AND MERRILL, M. A.: *Stanford-Binet intelligence scale: manual for the third revision form* L-M, Houghton Mifflin Co., Boston, Mass., 1960.
4. WECHSLER, D.: *The measurement and appraisal of adult intelligence*, 4th ed., Williams & Wilkins Company, Baltimore, 1958.
5. CHEVRIER, J.-M., GINGRAS, G. ET HÉBERT, B.: *Diagnosis of physical anomalies and rehabilitation prognosis obtained by joint study of the person and self drawings*, research project No. 604-12-34, Federal and Provincial Departments of Health, Rehabilitation Institute of Montreal, Montreal, 1963.
6. POROT, A.: *Manuel alphabétique de psychiatrie clinique et thérapeutique*, 2nd ed., Presses Universitaires de France, Paris, 1960.
7. ALEXANDER, F. *et al.*: *Psychoanalytic therapy: Principles and application*, Ronald Press Co., New York, 1946.
8. ALEXANDER, F. AND SHAPIRO, L. B.: *Neuroses, behavior disorders and perversions*. In: *Dynamic psychiatry*, edited by F. Alexander and H. Ross, University of Chicago Press, Chicago, 1952, p. 117.
9. NOYES, A. P.: *Modern clinical psychiatry*, 4th ed., W. B. Saunders Company, Philadelphia, 1953.
10. LUSSIER, A.: *Psychoanal. Stud. Child*, 15: 430, 1960.
11. WRIGHT, B. A.: *Physical disability: a psychological approach*, Harper & Brothers, New York, 1960.
12. KOLB, L. C.: *Disturbances of the body-image*. In: *American handbook of psychiatry*, vol. 1, edited by S. Arieti, Basic Books, Inc., New York, 1959, p. 749.
13. CRUCKSHANK, W. M.: *Editor: Psychology of exceptional children and youth*, Prentice-Hall, Inc., Englewood Cliffs, N.J., 1955.
14. WEINSTEIN, S. AND SERSEN, E. A.: *Neurology* (Minneapolis), 11: 905, 1961.